

Mr. Chairman and Members of the Committee:

I am pleased to be here today as you discuss issues related to the use of the Medicare hospice benefit. The twenty-first century will bring new challenges to the provision of palliative care to older people. Palliative care is changing, as are notions of a decent or “good” death free from unnecessary suffering for patients, families, and caregivers. New medical technologies and treatments are expected to result in better management of symptoms of chronic conditions and at the same time will blur the lines between curative care and palliative care.

Hospice care is an option available to Medicare beneficiaries who are expected to have 6 months or less to live and who choose to receive palliative care and supportive services, rather than traditional curative-focused medical care, to manage their terminal illness. Medicare-certified hospices provide a range of services to control pain and provide comfort, primarily to individuals in their own homes. Some patient advocates, hospice providers, and others contend that certain Medicare beneficiaries for whom hospice care is appropriate may have difficulty in gaining access to care or receiving services in a timely manner. However, officials of the Health Care Financing Administration (HCFA) and others assert that the hospice benefit is basically working as intended and meeting the needs of those who choose to use it. At your request, we examined the use of the hospice benefit during the past decade. Accordingly, my remarks will focus on (1) the patterns and trends in hospice use by Medicare beneficiaries, (2) factors that affect the use of the hospice benefit, and (3) the availability of hospice providers. Our report on this work is being released today, and it provides more detailed information on these issues.<sup>1</sup>

In summary, the number of Medicare beneficiaries choosing hospice services has grown substantially during the past decade—nearly 360,000 beneficiaries enrolled in 1998, more than twice the number that elected hospice in 1992. Cancer patients account for more than half of Medicare hospice users, but the most dramatic growth in use is among persons with other terminal conditions, such as heart disease, lung disease, stroke, or Alzheimer’s disease. Although more beneficiaries are choosing hospice, many are doing so closer to the time of death. Half of Medicare hospice users are enrolled for 19 or fewer days, and service periods of 1 week or less are common. Many factors influence decisions about whether and when to begin hospice services, including physician practices, patient preferences and circumstances, and general awareness of the benefit among professionals and the public. Along with these factors, federal oversight of compliance with Medicare eligibility requirements may also have affected hospice use. Growth in the number of Medicare hospice providers in both urban and rural areas and in almost every state suggests that hospice services are more widely available to program beneficiaries than in the past. At the same time, hospice officials report increased cost pressures from shorter patient enrollment periods and the use of more expensive forms of palliative care. Because data on provider costs are not available, however, the effect

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<sup>1</sup>Medicare: More Beneficiaries Use Hospice, But For Fewer Days of Care (GAO/HEHS-00-182, Sept. 18, 2000).

of these factors on the overall financial condition of hospice providers is uncertain. HCFA is beginning to gather information from hospice providers about their costs, which should allow the adequacy of Medicare hospice payment rates to be evaluated in the relatively near future.

## BACKGROUND

The Medicare hospice benefit, authorized in 1982 under part A of the Medicare program, covers medical and palliative care services for terminally ill beneficiaries. A Medicare-certified hospice provides physician services, nursing care, physical and occupational therapy, home health aide services, medical supplies and equipment, and short-term care in the hospital (for procedures necessary for pain control and symptom management). In addition, the hospice benefit provides coverage for several services not generally available under the regular fee-for-service Medicare benefit. These include drugs for symptom control and pain relief, inpatient respite care, and bereavement counseling for the patient's family. For each day a beneficiary is enrolled, the hospice provider is paid an all-inclusive, prospectively determined rate, depending on the level of care that is provided.<sup>2</sup>

Beneficiaries who elect hospice are required to waive Medicare coverage of care related to their terminal illness that is provided outside the hospice, although they retain coverage for services unrelated to their terminal illness. A beneficiary can cancel his or her election of hospice benefits at any time, return to regular Medicare, and reselect hospice coverage later. To be eligible for hospice services, a beneficiary's physician and the hospice medical director (or other physician affiliated with the hospice) must certify that the his or her prognosis is for a life expectancy of 6 months or less, if the terminal illness runs its normal course. This eligibility requirement has been a concern among patient advocates and providers, who assert that it deters referrals to hospice. Research has shown that it can be difficult for physicians to accurately predict whether or not a patient is likely to die within 6 months. It is particularly difficult to estimate life expectancy for persons with noncancer diagnoses because the course of their disease is often uneven.

## THE NUMBER OF BENEFICIARIES USING HOSPICE HAS GROWN AS AVERAGE DAYS OF USE HAVE DECLINED

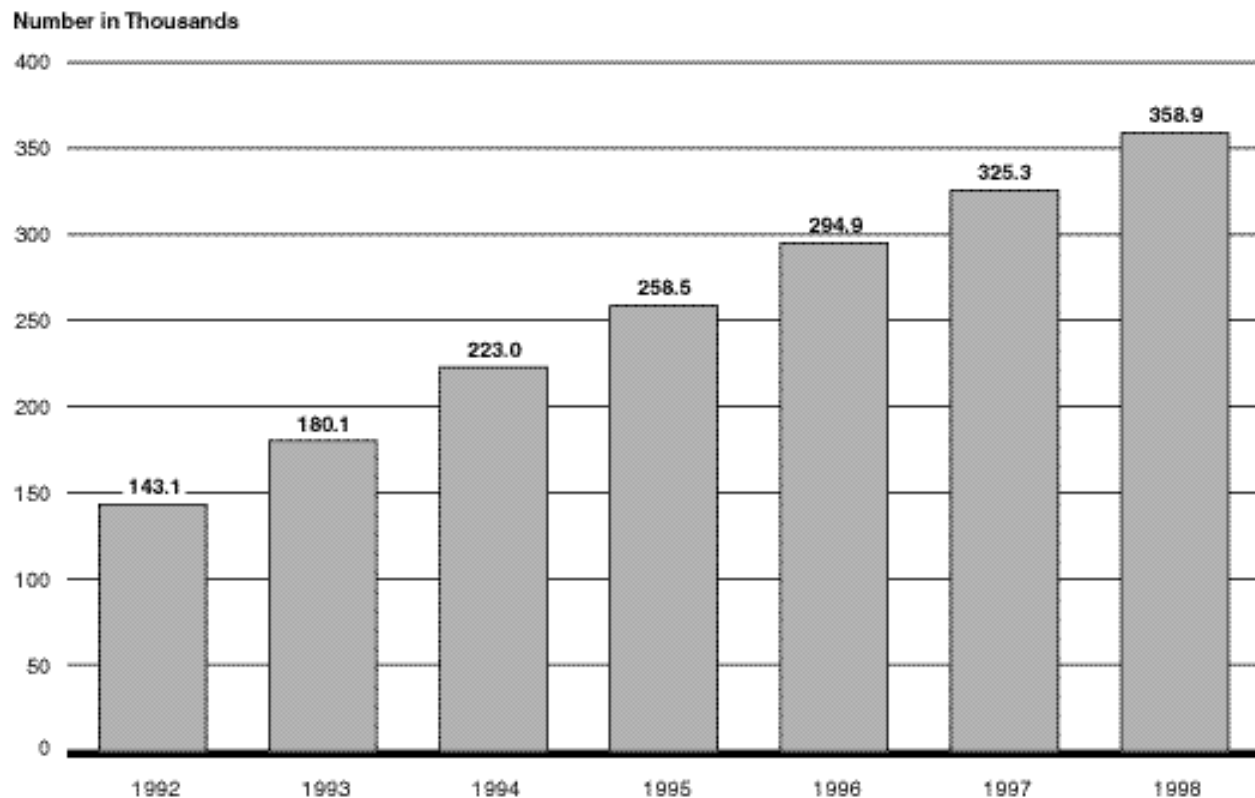
Our analysis of Medicare claims data indicates significant growth in hospice use. The number of beneficiaries electing hospice care more than doubled from 1992 to 1998, from about 143,000 to nearly 360,000 people annually. (See fig. 1.) In 1992, hospice users represented 1 in 12 Medicare beneficiaries who died that year. By 1998, this proportion grew to 1 in 5, with wide variation across states. However, this measure understates the proportion of Medicare beneficiaries who choose hospice care among those for whom the benefit was intended. According to a former president of the National Hospice

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<sup>2</sup>The four levels of hospice care are routine home care, continuous home care, inpatient respite, and general inpatient care.

Organization, “when the number of deaths nationwide is adjusted to reflect only those that are likely to be appropriate for hospice care, the percentage of dying patients cared for in hospice care is probably about 40 percent.”<sup>3</sup>

**Figure 1: The Number of Medicare Hospice Benefit Users Has Grown Steadily, 1992-98**



Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Given concerns about the difficulty of establishing a 6-month prognosis for beneficiaries with noncancer diagnoses, we took a closer look at their use of hospice services. Although the majority of beneficiaries electing hospice have a diagnosis of cancer, the use of hospice services by beneficiaries with noncancer diagnoses has increased dramatically. From 1992 to 1998, hospice enrollment by beneficiaries with cancer increased 91 percent, while enrollment among beneficiaries with all other conditions increased 338 percent. By 1998, about 43 percent of Medicare beneficiaries electing hospice had noncancer diagnoses, compared with about 24 percent in 1992. Table 1 shows the distribution of new hospice users by primary diagnosis in 1992 and 1998.

<sup>3</sup> John J. Mahoney, “The Medicare Hospice Benefit—15 Years of Success,” *Journal of Palliative Medicine*, Vol. 1, No. 2 (1998), pp. 139-46.

Table 1: Noncancer Patients are a Growing Share of Hospice Enrollees, 1992 and 1998

Primary diagnosis <sup>a</sup>	1992		1998	
	Number	Percent	Number	Percent
<b>All cancer</b>	<b>108,232</b>	<b>75.6</b>	<b>206,190</b>	<b>57.4</b>
Lung	29,966	20.9	57,841	16.1
Prostate	10,052	7.0	15,494	4.3
Breast	7,602	5.3	13,093	3.6
Colon	6,697	4.7	13,278	3.7
Pancreatic	6,359	4.4	12,116	3.4
Other	41,141	28.7	84,846	23.6
<b>All noncancer</b>	<b>34,878</b>	<b>24.4</b>	<b>152,759</b>	<b>42.6</b>
Congestive heart failure	6,141	4.3	24,248	6.8
Chronic obstructive pulmonary disease	4,112	2.9	15,765	4.4
Stroke	2,140	1.5	13,282	3.7
Alzheimer's disease	1,591	1.1	11,836	3.3
"Ill-defined conditions"	888	0.6	7,599	2.1
Other	20,006	14.0	80,029	22.3
<b>Total</b>	<b>143,110</b>	<b>100.0</b>	<b>358,949</b>	<b>100.0</b>

<sup>a</sup> Patients entering hospice may have more than one terminal condition or diagnosis. The data presented include only the first, or principal, diagnosis listed for each patient.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Beneficiaries who die of cancer are likely to receive hospice services during the course of their illness, more so than those with other conditions. In 1997, hospice users accounted for nearly half of all cancer deaths among Medicare beneficiaries aged 65 or older. For the most prevalent types of cancer in the hospice population, rates of use ranged from about 75 percent of deaths from brain or liver cancer to 31 percent for those with colon cancer. In comparison, hospice users represented 9 percent of people aged 65 and older who died from all noncancer causes in 1997.<sup>4</sup>

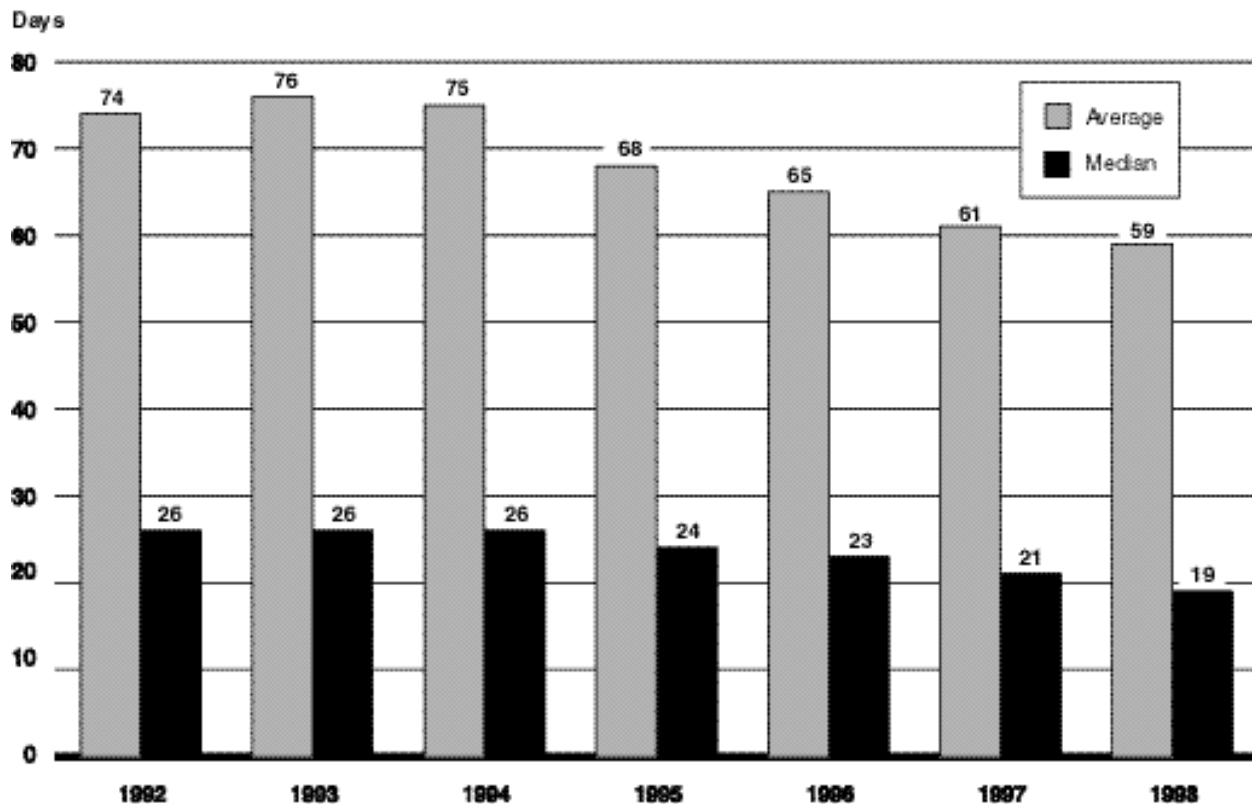
Although more Medicare beneficiaries are receiving hospice services, on average, they are receiving fewer days of care than did beneficiaries in the past. From 1992 to 1998, average length of stay declined 20 percent (from 74 to 59 days), while median length of stay declined 27 percent (from 26 to 19 days). (See fig. 2.) This overall decline appears to have been driven by both (1) a reduction in the proportion of beneficiaries with very long hospice stays and (2) an increase in the share of users with very short stays.<sup>5</sup>

<sup>4</sup> The denominator used for calculating noncancer use rates includes people who died unexpectedly (for example, from a first heart attack or injuries sustained during an automobile accident, and thus are not candidates for hospice care).

<sup>5</sup>The small proportion of beneficiaries with very long periods of enrollment skews the average length of hospice service. Although 97 to 98 percent of all those electing hospice complete their hospice use by the

Beneficiaries using hospice care for one week or less accounted for 28 percent of all users in 1998, compared with 21 percent in 1992. While 9 percent of beneficiaries received hospice services for more than 6 months in 1992, this share decreased to 7 percent in 1998.

**Figure 2: Average and Median Hospice Lengths of Service Have Declined, 1992-98**



Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

The decline in the average number of hospice days used has been especially dramatic among patients with a primary diagnosis other than cancer. While these beneficiaries historically had used many more days of care, the average number of days used declined 38 percent between 1992 and 1998. In comparison, average days used by hospice beneficiaries diagnosed with cancer declined by 14 percent. As a result, differences in length of stay across diagnosis categories have narrowed considerably. By 1998, cancer patients used 54 days, on average, while noncancer patients used 68 days.

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end of the year following their initial enrollment, our data for 1992 and 1993 show that some of the remaining 2 to 3 percent of beneficiaries may receive services for as many as 6 or 7 years.

## MULTIPLE FACTORS INFLUENCE THE USE OF HOSPICE BENEFITS

Several factors influence a beneficiary's choice about whether and when to use hospice care. These include physician preferences and referral practices, individual patient choice and circumstances, and general awareness of the benefit among the public and professional communities. In addition, recent federal oversight of compliance with patient eligibility requirements may have affected certain beneficiaries' use of the hospice benefit.

### Physician Practices, Patient Preferences, and Public Awareness Affect Hospice Use

Physicians initiate most referrals to hospice, and they may continue to care for their patients after enrollment as part of the hospice team. Because patients and their families rely heavily on physician recommendations for treatment, including recommendations for end-of-life care, physicians are an influential factor in a patient's entry into hospice. However, the research literature indicates that not all physicians are comfortable discussing end-of-life care, and some may hesitate to suggest hospice care for other reasons. Specifically, research has shown that many physicians are poorly trained in care of the dying and are often uncomfortable discussing options for end-of-life care or the cessation of curative treatment. In addition, some physicians may not be aware that they can continue to provide services after the beneficiary has entered hospice and may delay referral out of concern about losing control of the patient's care.

Even when the issue has been broached, some beneficiaries choose instead to continue curative or life-extending treatments. Medicare beneficiaries' use of hospice services requires acceptance that death is near. Once a patient is enrolled, no other services related to the patient's terminal condition are covered under Medicare. Beneficiaries who do not consider hospice care may be unwilling to confront the terminal nature of their illness. The Institute of Medicine (IOM) noted that patients in the United States are influenced by the general American unwillingness to accept limits of all types, including those of aging and death.<sup>6</sup> A Gallup poll in 1996 found that although a majority of people expressed interest in hospice care, most also said they would still seek curative care.

Beneficiary circumstances may complicate the initiation of hospice services. For example, because hospice is designed to allow the beneficiary to remain at home, some hospice programs limit participation to beneficiaries who have a caregiver at home. Improvements in cancer care and the addition of new treatment options for other common chronic conditions may be prompting some beneficiaries to pursue new curative options until very shortly before death, thus contributing to the trend of shorter hospice stays.

Public and professional awareness of hospice also influences the use of the Medicare benefit. The need for greater public and professional knowledge and awareness of

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<sup>6</sup> Institute of Medicine, Approaching Death: Improving Care at the End of Life (Washington, D.C.: National Academy Press, 1997).

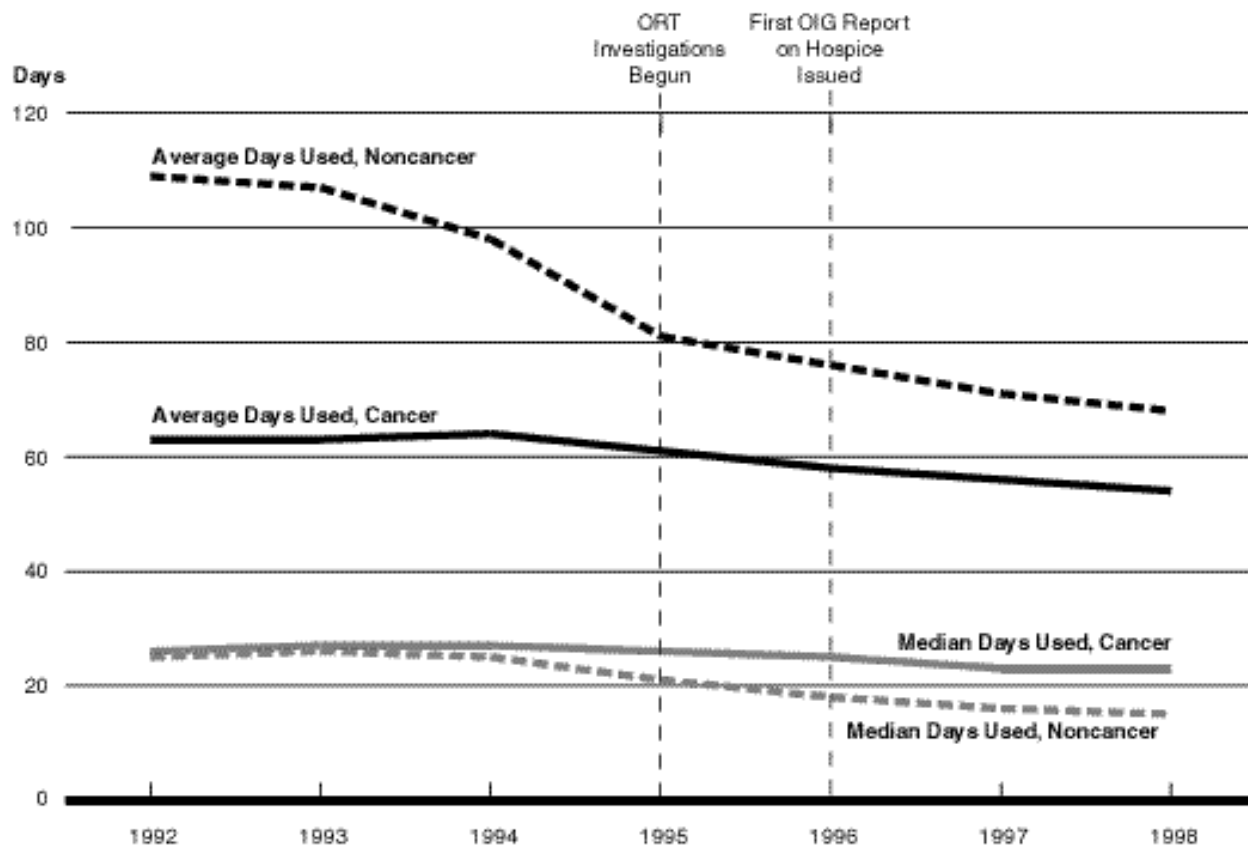
options for end-of-life care—including hospice—has been highlighted recently by the IOM, in recent congressional hearings, and in several other public forums. Patient advocacy groups, medical societies, and others have initiated a range of educational efforts designed to increase awareness of hospice care and its benefits. For example, the American Medical Association is developing a core curriculum for educating physicians in end-of-life care. The Medicare Rights Center, a consumer advocacy and education organization, is conducting a national campaign to increase awareness of the Medicare hospice benefit among health professionals. Also, the National Hospice and Palliative Care Organization has published a variety of materials on public education and outreach strategies for its members.

#### Federal Oversight of Eligibility May Have Had an Effect on Beneficiaries' Use of Services

In 1995 and 1996, the Department of Health and Human Services' (HHS) Office of the Inspector General (OIG) investigated the eligibility status of Medicare beneficiaries receiving hospice services, as part of a larger investigation of fraud and abuse in Medicare. Patient advocacy groups and the hospice industry assert that this federal scrutiny of compliance with the 6-month eligibility rule has had a chilling effect on entry into hospice for noncancer beneficiaries, for whom it may be more difficult to establish a 6-month prognosis with confidence. They contend that hospice providers are more cautious about admitting beneficiaries with noncancer diagnoses as a result, leading to delays in hospice entry for those wishing to use the benefit.

Although the percentage increases in beneficiaries electing hospice slowed somewhat from 1995 through 1998 compared with earlier years, it is difficult to know how much of this slower growth is attributable to the effect of federal scrutiny and how much is attributable to other factors, such as the larger base of beneficiaries already using hospice. Importantly, the trend toward fewer average days of hospice use began before the period of federal scrutiny, as shown in figure 3.

**Figure 3: Decline in Days of Hospice Care Began Before Federal Scrutiny Increased**



Note: Operation Restore Trust (ORT) was a joint initiative between HCFA, the Office of Inspector General, and the Administration on Aging designed to identify vulnerabilities in the Medicare program.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

While the OIG reviews were under way, the National Hospice Organization developed guidelines to assist physicians and hospices in determining a 6-month prognosis for patients with selected noncancer diagnoses. These included amyotrophic lateral sclerosis (ALS), dementia, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), heart disease, pulmonary disease, liver disease, stroke and coma, and kidney disease. In order to enhance accuracy and uniformity in the claims review process, HCFA distributed these guidelines to the intermediaries that process hospice claims for Medicare.<sup>7</sup> The intermediaries have since adapted them for use as formal local medical review policies, which specify clinical criteria for

<sup>7</sup> Intermediaries contract with HCFA for paying providers for services provided to Medicare beneficiaries. They review all hospice claims for accuracy and completeness before payment and review a sample of claims to confirm that beneficiaries were eligible for the hospice services provided.



establishing a patient's 6-month prognosis.<sup>8</sup> Intermediaries report that they allow for variation in individual cases. For example, one medical review policy for heart disease states that "some patients may not meet the criteria, yet still be appropriate for hospice care, because of other comorbidities or rapid decline."

HCFA instructed the intermediaries to begin medical review of hospice claims in 1995. Prior to that year, a very small proportion of claims were reviewed. Four of the 5 intermediaries reported that, by 1999, review rates ranged from 0.8 to 4.2 percent of all hospice claims processed.<sup>9</sup> They noted that claims are selected for medical review based on a variety of factors, including beneficiary length of stay, beneficiary diagnosis, and provider use of hospice continuous home care or inpatient care.

#### HOSPICE CARE IS MORE WIDELY AVAILABLE, BUT PROVIDERS REPORT COST CONCERNS

Sustained growth in the number of hospice providers participating in Medicare and in their distribution throughout the country suggests that hospice services are now more widely available to program beneficiaries. While all sectors of the hospice industry have grown over the past decade, recent growth has been particularly strong in the for-profit sector and among large hospice programs. At the same time, hospice industry officials report growing cost pressures from shorter patient stays and changes in the practice of palliative care. However, because data on provider costs are not available, it is not clear how these cost factors affect providers and beneficiaries.

Until recently, the number of hospices participating in Medicare had grown each year. As shown in figure 4, the number of Medicare-certified hospice providers nationwide grew by 82 percent, from 1,208 in 1992 to 2,196 in 1999.<sup>10</sup> Each year during this period, additional hospice programs became certified for Medicare, although the number of new entrants declined from 274 in 1994 to 46 in 1999, and the number of hospices leaving Medicare exceeded the new entrants in 1999. (Many of those leaving were based in home health agencies which may have closed because of changes in home health agency payments enacted in the Balanced Budget Act of 1997.) The higher number of providers reflects not only new hospices but also growing participation in Medicare. In 1989, we estimated that about 35 percent of the approximately 1,700 hospice providers nationwide participated in Medicare. By 1998, the National Hospice and Palliative Care Organization estimated that 80 percent of hospices were certified to serve Medicare patients.

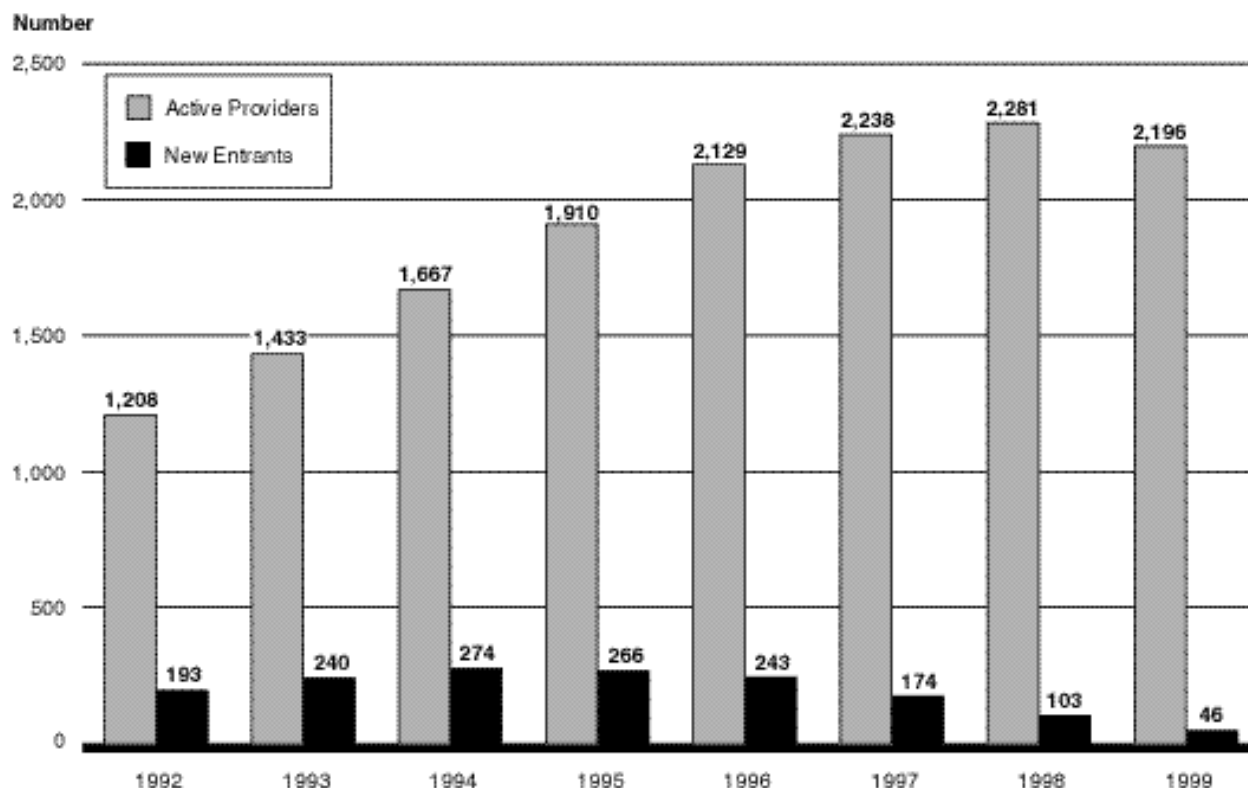
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<sup>8</sup> Local medical review policies are medical criteria, specific to a service or diagnosis, that may assist in determining compliance with program eligibility requirements.

<sup>9</sup> One fiscal intermediary did not provide data on rates of medical review.

<sup>10</sup> The total number of Medicare hospice providers peaked at 2,281 in 1998. In 1998 and 1999, hospice program closures (195) exceeded new program entrants (149) for the first time. A disproportionate number of hospice closures were among those based in home health agencies. Although HHA-based hospices represent approximately one-third of all hospices, they accounted for 43 percent of those that closed over the 2-year period. As we reported in Medicare Home Health Agencies: Closures Continue, With Little Evidence Beneficiary Access Is Impaired, (GAO/HEHS-99-120, May 5, 1999), 14 percent of home health agencies closed between October 1997 and January 1999.

**Figure 4: Growth in the Number of Medicare Hospices and New Entrants, 1992-99**



Source: GAO analysis of annual Medicare Provider of Service Files.

Over this period, all types of hospice providers grew, in rural and urban areas, and in almost every state. From 1992 to 1999, the rate of growth was greatest among for-profit providers and those in rural areas. Also, large providers accounted for an increasing share of the services delivered. (See table 2.) The number of for-profit providers increased nearly fourfold and the number of large hospice programs (those serving 500 or more patients per year) more than tripled over the period. In addition, the number of rural providers increased 116 percent while the number of urban-based providers increased 64 percent. Even with high growth in these sectors of the industry, the majority of hospices are small programs (with fewer than 100 patients per year), organized as not-for-profit, and located in urban areas.

**Table 2: Growth in Medicare Hospice Programs by Provider Characteristics, 1992 and 1999**

Characteristic	Number of hospices		Percent change 1992-99
	1992	1999	
All hospices	1,208	2,196	82
<b>Type</b>			
Freestanding	466	877	88
Hospital-based	327	553	69
HHA-Based	403	730	81
<b>Control</b>			
For-profit	151	593	293
Not-for-profit	957	1,365	43
Government	63	146	132
Other	36	75	108
<b>Location</b>			
Urban	823	1,350	64
Rural	384	829	116
<b>Size<sup>a</sup></b>			
Small	795	1,244	56
Medium	370	816	121
Large	43	136	216

<sup>a</sup> We categorized hospices as small if they served fewer than 100 Medicare beneficiaries a year, medium if they served 100 to 499 patients a year, and large if they served 500 or more beneficiaries a year.

Source: GAO analysis of annual Medicare Provider of Service Files.

Even as the hospice industry has grown, changes in the use of the hospice benefit and the delivery of hospice care have raised cost concerns among providers. Industry representatives point out several areas of change that they contend are adversely affecting the financial condition of providers. Specifically,

- Under Medicare's per diem payment system for hospice care, hospices have traditionally offset the higher cost days that occur at admission and during the period immediately preceding death with lower cost days of less intensive care.<sup>11</sup> For example, costs for admitting and assessing a new patient, establishing a care plan, and delivering medical equipment are incurred during the first few days of enrollment and do not vary with the patient's period of service. As enrollment periods have declined, hospices have fewer

<sup>11</sup>Hospice representatives we interviewed reported that the hours of nursing, social work, and administrative time the typical patient requires are nearly twice as great during the first and last weeks of a patient's care as they are during the intervening weeks.

days over which they can spread the higher costs associated with the start and end of a patient's stay.

- As more patients enter hospice later in the course of their terminal illness, they enter with higher levels of impairment and in need of more intensive services. In addition, the shift in the mix of patients by diagnosis may have increased the average service needs for the overall hospice population. According to the most recent National Home and Hospice Care Survey, hospice patients with noncancer diagnoses are somewhat more likely than those with cancer to be functionally impaired and thus may require more services on a regular basis from hospice agencies.<sup>12</sup>
- Physicians and patients are calling on hospice programs to provide a broader array of palliative services than in the past. Costly treatments such as chemotherapy and radiation—traditionally used for curative purposes—are increasingly used in the hospice setting to manage pain and other symptoms. Furthermore, some new palliative care treatment options, such as the transdermal administration of narcotic pain medication, may offer better symptom control for some patients but often at greater expense.

Data to assess how declining patient stays and changes in palliative care have affected overall provider costs are not available. While specific, more expensive services may be provided more frequently, the share that these services currently represent of total costs is unknown. Furthermore, we do not know the extent to which providing more expensive medications or treatments to hospice patients may reduce the need for other services such as nursing visits. HCFA, in response to the Balanced Budget Act requirements, has begun collecting hospice cost data to use for evaluating the adequacy of current levels of Medicare reimbursement. Officials anticipate that audited hospice cost data will be available beginning in late 2001.

## CONCLUSIONS

Trends in the use of the Medicare hospice benefit during the 1990s indicate that beneficiaries with all types of terminal diseases are making use of hospice services in greater numbers every year. In particular, the types of patients selecting hospice have expanded broadly—from mostly beneficiaries with cancer to a nearly even split among those with cancer and those with other chronic conditions. In spite of these trends in use and the widespread availability of hospice providers, patient advocates and the industry are concerned that the Medicare hospice benefit is underused. Because many factors influence the use of hospice care, however, potential demand is difficult to determine. The goal remains that the program ensure that beneficiaries understand their rights and options and receive appropriate care that is tailored to their needs and preferences at the end of life.

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<sup>12</sup>National Center for Health Statistics, The National Home and Hospice Care Survey: 1996.

Mr. Chairman, this concludes my statement. I would be happy to answer any questions from you and other members of the Committee.

**GAO CONTACT AND ACKNOWLEDGMENTS**

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